DOCUMENT RESUME

ED 279 987 CG 019 796

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TITLE Integrating an HTLV-III Screening Program into a Community Based Family Health Service Agency.
PUB DATE 30 Sep 86
NOTE 13p.; Paper presented at the Annual Meeting of the American Public Health Association (114th, Las Vegas, NV, September 28-October 2, 1986).
PUB TYPE Reports - Descriptive (141) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Community Health Services; *Disease Control; *Family Planning; Females; High Risk Persons; *Perinatal Influences; Pregnancy; Prevention; Public Health; *Screening Tests
IDENTIFIERS *Acquired Immune Deficiency Syndrome; *Human T Lymphotropic Virus III

ABSTRACT

Acquired Immune Deficiency Syndrome (AIDS) has become one of the most serious epidemic disease problems in recent years. In 1985 the Public Health Service recommended establishment of test sites where individuals might be tested for Human T Lymphotropic Virus III (HTLV-III) antibody. An HTLV-III antibody screening program was integrated into a community-based health service agency which focused on reproductive health care. The HTLV-III antibody screening program provided a needed testing and counseling service to community residents. Both staff members and community residents benefited by having pertinent and accurate information on AIDS available and accessible. The literature indicates that providing HTLV-III screening and counseling for women of reproductive age prior to their becoming pregnant is the most effective way to prevent perinatal transmission of the virus. Family planning programs with females at risk have a responsibility of providing information and making available testing for the HTLV-III antibody to provide women information regarding the risk. Sensitivity to staff, clients, and community concerns is imperative in implementing an HTLV-III screening program. Careful consideration needs to be given to site, scheduling, voluntary participation, anonymity, and confidentiality as well as clinical services in order to have a successful program. Appendices include information sheets on the blood testing program and procedures. (NB)

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# INTEGRATING AN HTLV-III SCREENING PROGRAM INTO A COMMUNITY BASED FAMILY HEALTH SERVICE AGENCY

The American Public Health Association Annual Meeting
Las Vegas, Nevada
September 30, 1986

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CG 019796

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## INTRODUCTION

The Acquired Immune Deficiency Syndrome (AIDS) has emerged in the last few years to become one of the most serious epidemic disease problems in recent history. It has been designated the nation's number one health problem by the Health and Human Services Secretary and consumes an increasing proportion of the nation's health resources.

The majority of the reported AIDS cases are sexually active homosexual or bisexual men with multiple partners. The other high risk groups, both male and female, are present or past abusers of intravenous drugs; persons with hemophilia or other coagulation problems; heterosexual contacts of someone with AIDS or at risk for AIDS; and persons who have had transfusion with blood or blood products prior to March, 1985. Approximately 6% do not fall into any of these groups. Infants and children who have developed AIDS may have been exposed to the HTLV-III virus in utero, during birth or shortly thereafter. Informing and educating childbearing age women at risk for AIDS about the dangers to their babies from infection before pregnancy is the most effective tool against the perinatal transmission of AIDS.

This paper will describe the introduction and implementation of an HTLV-III screening program in a community based health service agency whose major focus is reproductive health care.

## BACKGROUND

In January, 1985, the Public Health Service (PHS) published its recommendations for screening donated blood and plasma for antibody to the virus (HTLV-III) causing AIDS. In February, 1985 the Food and Drug Administration (FDA) sent a memo to all registered blood banks notifying them of the imminent licensure of tests to detect antibody HTLV-III virus and recommending that provision be made for medical follow-up and donor counseling by blood banks. They also recommended establishment of alternate test sites where individuals concerned for their past exposure to HTLV-III virus might obtain test results without donating blood.

Soon after these recommendations the Center for Disease Control announced the availability of federal funds for the establishment of alternate testing sites to perform HTLV-III antibody testing. Funding was received by the Division of Acute Infectious Disease Epidemiology in Pennsylvania to begin alternate site testing and/or counseling programs in counties where most AIDS cases had been reported statewide. Family Health Services had a pre-existing contract with the State Health Department to provide screening, diagnosis and treatment of sexually transmitted disease. The agency was asked to contract as an alternate testing site for HTLV-III antibody testing. There were no start-up monies provided to implement the program but supplies and laboratory test cost were covered by the grant. The grant also provides an eleven dollar ($11) reimbursement for each visit to the agency.

AGENCY DESCRIPTION

Family Health Services is a private, non-profit community based health corporation established in 1970 by Centre County citizens concerned about the lack of family planning services in their community. There is a voluntary Board of Directors and a paid staff of 40 full and part-time workers. Approximately 90% of the direct care services are provided by four certified registered nurse practitioners, three registered nurses and one physician assistant in collaboration with a physician who serves as the Medical Director.

It began with a small core of volunteer staff providing family planning services to low-income women at a clinic site located in Bellefonte, Pennsylvania who otherwise often went without these services. An active caseload of over 6,000 female clients with a total of over 11,000 individual clinic visits per year for family planning clinic services comprise the majority of those seen in the agency. Direct services to males was first offered in 1981 with the initiation of a sexually transmitted disease program for both men and women funded by the Pennsylvania Department of Health. A total of 416 men were served in fiscal year 86.

The agency provides services in a metropolitan statistical area in Pennsylvania which is located in the geographic center of the State. State College is the largest population base of the metropolitan statistical area.

In addition to family planning services at all three clinic sites, Family Health Services has grown to offer a variety of family-oriented services. These services include supplemental foods and nutrition education through the WIC program; child and young adult health screening through the EPSDT program; screening, diagnosis and treatment of sexually transmitted diseases through the State STD program; genetic screening and education; infertility information and referral; and cervicography, colposcopy and cryosurgery. Community education group sessions for individuals or families are offered on pregnancy and parenting as well as screening for reproductive cancer.

PLANNING AND IMPLEMENTATION OF PROGRAM - INITIAL PHASE

New programs offered by the agency require prior approval by the Board of Directors. When presented to the Board, concerns and fears were expressed by several members. Some thought "this was a service outside the mission of the agency. If the service is provided, it may affect the image of the agency and deter the clients we are there to serve. Clients may not come into the clinic sites if they know there may be a person in the waiting room with AIDS." Board members wanted assurance that provision of services by staff members would be voluntary. They also emphasized the need for confidentiality.

Several staff members were polled regarding their thoughts on providing the service. In one clinic site the staff thought it was a good idea but didn't think it would work out at their work place "because of community attitude." "When people here find out that AIDS testing is being done in the clinic they won't come in." Concerns were expressed regarding risk factors for those clinical people coming into direct contact with persons coming in for screening.

It became apparent that careful planning was necessary in order to implement the program successfully. There was a need for valid information being provided to both board and staff members.

Prior to Board approval to provide the service a nurse practitioner who is also the State College Clinic Manager agreed to be the contact person and coordinate the HTLV-III testing program if approved. The testing program was discussed with an RN who already was drawing serologies for syphilis testing on STD clients. She expressed some fears about personal risk and contracting AIDS if she participated. After being provided with information regarding precautions in handling blood samples which is essentially the same as she had been following and information regarding low risk in the type of health care setting she agreed to continue drawing blood samples. In reviewing the precautions it became apparent that more care needed to be taken when drawing blood samples for syphilis testing and disposal of blood filled microhematocrit tubes as well as lancets. We were able to improve the agency's infection control procedures.

After Board approval the program was introduced to the medical receptionist and financial clerk who answer the telephones and schedule appointments. They expressed a lot of uncertainty. One concern was that "we would be deluged with phone calls for appointments making it difficult to schedule family planning clients."

Any and all valid information regarding AIDS or HTLV-III testing was given to all staff members in the designated alternate testing site to read and discuss. Many fears were allayed through accurate and appropriate information at crucial times.

Just prior to finalizing the preparation to implement the service the State Health Department prematurely sent a press release to the local newspaper indicating that the HTLV-III testing was available at the State College clinic site and to call for appointments. This created tension and concern within the agency at all levels. There were many gaps that existed. More information was needed before scheduling appointments. At the agency's request a State Health Department epidemiologist came to the agency to present information on HTLV-III testing and AIDS to all clinical staff from all three clinic sites. It provided an opportunity for many questions to be asked regarding fears and

concerns. It also was helpful in working out some of the gaps that existed. For example, we had no lab slips to send with specimen for HTLV-III testing. It was also unclear how the lab slip would be tracked. How would confidentiality be maintained if the sample was sent to several labs was another question. The State Health Department provided us with the release forms and information regarding testing procedure, contract laboratory and confidentiality. See Appendix A, B, C, D.

Separate presentation on the HTLV-III screening program were given to the Board and all agency staff members explaining the program operationally in the agency by the Coordinator. This provided further opportunity for concerns to be discussed and valid information to be given.

As of September 1, 1986, 21 males and 5 females have been precounseled regarding HTLV-III. The majority of these did not make an appointment for HTLV-III screening but while there for other reasons determined to be in the high risk category and provided with information regarding the testing (14 males, 3 females).

An interesting observation is that many who are scheduled for appointments to obtain tests results do not keep their appointments and have to be contacted to make another appointment. The possible reason for this may be related to fear of outcome of test results. An arrangement has been made with a mental health counselor to be available to do further counseling if needed by those persons who have been informed.

Appointments for HTLV-III screening were integrated into the daily appointment times along with family planning, STD and routine physical exams. This provided a more comfortable situation for all clients because the agency is a multi-service site which makes it difficult to identify why someone may have scheduled an appointment. The waiting room area is also utilized by mental health Counseling Services clients who share office space with the agency.

Due to the media coverage regarding "AIDS" the agency receives phone calls for information on a regular basis. Fears, concerns, and misinformation are

commonly expressed. Following are some examples of phone calls received and situations encountered during pretest counseling sessions.

1. A woman phoned and "demanded that we guarantee her that we would test her husband for AIDS if she made him come into the clinic."
2. 15 year old female who requested testing because her boyfriend of one month with whom she had sex two weeks ago (her first time) had been in jail. Someone had informed her that it was rumored that the boyfriend had a male cell mate and they had sex while in jail.
3. 36 year old gay who refused to give name because if his lover (long-term relationship) ever found out he was there for testing he would "kill him." He said he "did not trust his male lover."
4. 20 year old nursing student who regularly was selling serum to a lab was told that they no longer could accept her serum because of a positive Initial Elisa test for AIDS." Referred to us for further testing and counseling.
5. Several former intravenous drug users (2 male, 1 female - female considering starting a family in near future) who had shared needles now in rehab program - "just want to know."
6. Several males chose not to be tested because "practice safe sex anyway and what good does it do anyway to know since there is no cure if you develop AIDS."
7. 27 year old gay who was sure he had AIDS because he "has a sore on his penis which just won't heal." History revealed testing done for gonorrhea and syphilis at another facility two weeks ago which were negative. Antibiotic prescribed for "sore on penis" - completed one week ago. Client related that he had been applying "black tar salve and bandaids to try to get it to heal up." On exam no open lesions noted but irritated reddened area most likely from adhesive on bandaids.

SUMMARY

Integrating an HTLV-III antibody screening program into a community based health service agency has provided a needed testing and counseling service to residents of our community. Staff members and the community at large have also benefited by having pertinent and accurate information on AIDS available and accessible.

The literature indicates that providing HTLV-III screening and counseling for women of reproductive age prior to becoming pregnant is the most effective way to prevent perinatal transmission of the virus. Family planning programs with females at risk have a responsibility of providing information and making available testing for the HTLV-III antibody to provide women information regarding the risk.

Sensitivity to staff, clients and community concerns are imperative in implementing an HTLV-III screening program. Careful consideration needs to be given to site, scheduling, voluntary participation, anonymity, confidentiality as well as clinic services in order to have a successful program.

## TESTING PROCEDURE FOR HTLV-III ANTIBODY

1. The patient is given pretesting information and then reads and signs the informed consent forms. (Appendix B)
2. A copy of the completed form should be given to the patient. Approximately 10 ml of blood is drawn from the patient.
3. The laboratory slip using a patient I.D. number is used to identify the client. The clinician must also complete the PATIENT STATUS part of the form and check the most appropriate box: H/B for a gay or bisexual male patient; IV for an intravenous drug user; CT if the patient is a suspected sex partner of an AIDS patient, or ARC patient, or probable AIDS or ARC patient; and OTHER for all other patients.
4. An ELISA test (acronym for enzmye-linked immunosorbent assay) will be performed on the sample. If this test is negative, then no other tests will be done. If it is positive, the test will be sent to Lionville and be repeated. If it is again positive, the sample will be considered reactive or positive. A Western Blot test will be done on all positive ELISA samples. The results are sent from the State lab in Lionville to the State Health Department who then send us computer print-out of results.
5. The turn-around time for both tests is about 14 to 21 days. The patient should be told when to call back at the time the blood sample is drawn.
6. To avoid complications, hemophiliacs should not be treated at alternate sites or STD clinics but should be referred to their private physician for HTLV-III testing.
7. All test results should be given at the time of the post-test interviews. No results should be reported to anyone by telephone. We schedule these all for three weeks from the time of HTLV-III testing.

IMPORTANT INFORMATION
ABOUT BLOOD TESTS FOR THE PRESENCE OF
HUMAN T LYMPHOTROPIC VIRUS III (HTLV-III ANTIBODY)

WHAT IS HTLVI-III? HTLV-III is a virus which is the cause of the Acquired Immune Dificiency Syndrome (AIDS) and the AIDS Related Complex (ARC). AIDS is a disease which destroys the body's immune system, making the individual susceptible to certain types of cancer and infections. Many AIDS patients die. There is no treatment or preventive medicine for AIDS. ARC is a group of symptoms which are not fatal and are not specific, such as weight loss, fever, and diarrhea. At the present time there is no information which indicates which people infected with HTLV-III virus will develop AIDS or ARC. The HTLV-III virus may remain in the body for many years and can be transferred to others by sexual contact, by blood or blood products, and by intravenous drug abuse.

HOW IS MY BLOOD TESTED FOR HTLV-III INFECTION? HTLV-III infection produces antibodies in the blood. Your blood will be tested for antibodies to the HTLV-III virus. Some antibody tests may be borderline, in which case the test is performed again. It may also be checked by different test procedures. The results of your test will be reviewed with you, and recommendations made to you depending upon your test result.

People at increased risk of exposure to the HTLV-III virus are those who:

1. Are gay or bisexual males.
2. Abuse injectable drugs, such as cocaine or heroin and share needles when using these drugs.
3. Have been treated for hemophilia.
4. Have received blood transfusions or other blood products before March 1985.
5. Are sex partners of any persons mentioned above or sex partners of people with AIDS, ARC or positive HTLV-III Antibody Tests.

**********

I have read the information on this form about HTLV-III antibody tests and have had the chance to ask questions which have been answered to my satisfaction. I request that a blood specimen be collected from me.
I understand that the results of this test are confidential by law and will not be released absent a valid consent form signed by me. I also understand that non-identifiable information obtained from this test may be used for statistical analyses by Department of Health employees or collaborating researchers designated by the Department of Health. Use of any identifiable information, for any purpose, will require my written consent.

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INFORMATION ON PERSON REQUESTING AN HTLV-III ANTIBODY TEST (PRINT!)

---

Last Name First Name MI Birthdate Age

_____

Address Telephone

_____

City County State Zip

_____

Signature of person to be tested Date

X_____

Date Blood Drawn_____

Name of Person Counseling_____

HTLV-III ANTIBODY TESTING PROGRAM

CONTRACT LABORATORY INFORMATION

Regional Clinical Laboratory

1526 Peach Street

Erie, PA 16501

Telephone: 814-453-3611

Supplies:

HTLV-III Laboratory Slips

Vacutainers

Needles

Needle Holders

Postage Paid Mailers

Note: S.T.D. Clinics that now submit blood to Regional Clinical Laboratory need not submit another specimen for the HTLV-III test. Both the RPR and the HTLV-III test will be done on the same specimen. For the remaining non-STD State Health Center sites, only the HTLV-III test will be performed. All "positive" HTLV-III specimens will be sent by Regional Clinical Laboratory to the state Bureau of Laboratories (telephone number 215-363-8500) in Lionville for a Western Blot test.

## CONFIDENTIALITY - ALTERNATE SITES

To protect the confidentiality of the patients, a coding system may be used. The patient's code should be entered on the informed consent form. One copy of the completed consent form should be given to the patient. A sample code follows:

Pt. I.D.: 062186-231-13

The first six digits refer to the date that the blood sample is collected. The above date is June 21, 1986.

The next three digits refer to the site code. In this case, 231 indicates the State Health Center in Delaware County. All sites will have a unique three digit identifier.

Patients will be numbered consecutively as they appear for testing. Thus, the 13 indicates that the patient was the 13th patient at the State Health Center site on June 21st. If tests have to be repeated for the same patient, the same I.D. code should be used. A copy of the codes is included in this packet. Blood samples can be identified by this system of patient codes.

A patient history card, preferably 4" x 6", should be kept for each patient. Column headings should include: patient I.D. number, name, address, age, sex, race, pre-counseling date, date sample drawn, date sent to lab, date of results, type of test, post-counseling date, name of counselor, and other information you may wish to record.

In addition, a daily log sheet should be kept with similar information: patient I.D. number, date specimen was drawn, date to lab, name of lab, date results received, type of test performed, counseling dates, and any additional information that would be valuable to you.

All records are confidential and should only be handled by the counselors. When not in use, all records should be locked up for security purposes.